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ABSTRACT

This document presents one module in a set of training resources for trainers to use with parents and/or professionals serving children with disabilities; focus is on stress and support in the family. The modules present content and activities that build skills and offer resources to promote parent-professional collaboration. Each module takes about 2 hours to deliver. The module guide has eight sections: a publicity flyer, topic narrative, overview, trainer agenda, activities, summary, bibliography, and evaluation. Introductory information explains how to use the modules including conducting a needs assessment, planning the training, selecting the training module, implementation, evaluation, and followup. Objectives of this module are: (1) become familiar with the Universal Family Life Cycle, (2) develop an awareness of issues and stress in the family with a child with disabilities, (3) discuss factors that determine stress for families and identify the various coping strategies, (4) select the various informal support systems that reduce family stress, and (5) understand the need for a balanced individual and family life. A bibliography identifies 12 books, magazines, or other resources. (DB)

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STRESS and SUPPORT in the FAMILY

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California State Department of Education
Special Education Division
Program, Curriculum and Training Unit

Presents A Module on:

Stress and Support in the Family

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1988

This module, as well as thirteen others, were produced under the direction of Karl E. Murray and Susan Westaby of the Program, Curriculum and Training Unit, Special Education Division, CA State Department of Education. The modules are being field-tested throughout 1988. During this field-test stage, they are available by sending \$ 5.00 for each module (includes tax and mailing) to: Parent Training Modules, CA State Department of Education, P.O. Box 944272 - Room 621B, Sacramento, CA, 94244-2720. Make checks payable to Parent Training Modules.

INTRODUCTION

The Parent/Professional Training Modules have been developed to serve as a core set of training resources for trainers to use primarily with groups of parents. Some of the trainings were designed specifically for combined groups of parents and professionals, and all the trainings can be adapted for use with parents or professionals as separate or combined audiences. The training modules in the series focus on content and activities that build skills and offer resources to promote parent-professional collaboration to ensure quality education for all students with disabilities. There are fourteen training modules in this series:

- Parent Professional Collaboration**
- Parental Involvement**
- Stress and Support in the Family**
- Coping with Loss and Change**
- Parent Support Groups**
- An Effective Community Advisory Committee**
- Community Advisory Committee Leadership Training**
- Communication Skills**
- The Individualized Education Program: Rights and Responsibilities**
- Placement in the Least Restrictive Environment**
- Training for Professionals Working with Families**
- Parent Professional Collaboration in Planning for Employment**
- Transition Planning**
- Interagency Collaboration: The Parents' Role**

Each training module has eight sections:

- Flyer**
- Topic Narrative**
- Overview**
- Trainer Agenda**
- Activities**
- Summary**
- Bibliography**
- Evaluation**

Within each of these sections there are these materials:

Flyer - The Flyer highlights what participants can expect to learn by attending the training. It can be personalized for each training by adding date, time, and location in the appropriate spaces.

Topic Narrative -- The Topic Narrative contains content information specifically for the trainer. Trainers use the information to enhance their knowledge and understanding of the subject matter of the training module.

Overview -- The Overview contains the goals and objectives for the module; and the content and presentation strategy for each activity contained within the module.

Trainer Agenda -- The Trainer Agenda contains details of trainer and participant activities, materials and media. It is a suggested agenda that trainers can personalize to fit their style and the specific needs of the participants. A few modules that deal with sensitive or difficult content have Trainer Tips included in the Agenda section.

Summary -- The Summary contains highlights of all the content information presented in activities within the training. The Summary was designed to provide information to prospective participants and to workshop planners.

Bibliography -- The Bibliography contains the names of books, magazines and other resources that were used as references in developing the training modules and may serve as a list of suggested reading materials for trainers as well as participants.

Evaluation -- The Evaluation contains questions that directly assess the objectives of the module as well as some general questions to evaluate the usefulness of materials and trainer effectiveness.

The Parent/Professional Training Modules have been designed to be a flexible and expandable resource for trainers of parents and professionals. It can be housed in binders or in file folders and rearranged as needed. Trainers are urged to add articles, resources and other materials that will make each training reflect their individual style and meet the needs of the participants.

HOW TO USE THESE TRAINING MODULES

Conduct a Needs Assessment:

Gather as much information as you can about the groups that you will be working with. The following types of questions may help:

Does the group meet regularly or is it assembled specifically for the purpose of this training?

What does the group want to accomplish? Does it have a stated goal? Are there a set of outcomes that the group wants to achieve?

Who is involved in the group (agencies and organizations)?

If the group is an ongoing group, how is the group organized? (officers, executive committee, standing committees, task groups, etc.)

What has the group already done? What training has the group already received?

What is the group working on now?

How does the group get things done?

Has the group conducted a needs assessment to determine the group's need for training and the training topics of interest?

Plan the Training

Typically, this is a dialogue between the trainer and the client. Often, the client will have a specific topic or activity in mind. Sometimes additional topics will be suggested during the needs assessment process when the trainer probes to get more information. The trainer can share a list of module topics and/or several module summaries to aid the client in selection of a topic(s) from the series.

Select the Training Module

The Parent/Professional Training Modules offer a wide selection of topics and activities. The trainer can select the module that deals with the topic chosen by the client.

Review the Training Module

The module provides the core activities and a suggested trainer agenda. The trainer can adjust both to reflect their individual style and the needs of the client.

Identify Additional Resource Materials

The trainer can add articles, resources, and other materials to the core training module. Often a trainer will introduce local resources or pertinent sample materials.

Deliver the Training

The Parent/Professional Training Modules are best delivered by a training team of a parent and a professional. Collaboration is modeled by the team as each member of the team displays unique perspectives, abilities and knowledge as they enhance each others presentation styles.

Evaluate the Training

Evaluation is an essential element of any training. Each module includes an evaluation that assesses the specific objectives of the module and the usefulness of materials. These evaluations can assist the trainer in refining the module content and modifying presentation style, if needed.

"Follow-Up" the Training

It is a good practice to follow-up any training with a personal visit, letter, or a phone call. The trainer may wish to keep a list of names, addresses, and phone numbers of participants to facilitate follow-up. The follow-up usually consists of discussion about how the training may have impacted the client's personal or professional life. Clients may express the desire for further training and/or materials and resources.

Stress and Support in the Family

(For All Interested and Involved Parents)

You, as a participant, will learn about:

- the Universal Family Life Cycle
- factors that cause stress in your family
- ways to cope
- informal support systems
- a balanced individual and family life style

Day and Date:

Time:

Location:

For More Information, CALL:

Please Come

Stress and Support in the Family

Topic Narrative

All families experience change as members are born, grow-up, leave home and bring in new members through marriage or other relationships. The Universal Family Life Cycle is common to most cultures. The cycle is:

Couple
Early Childhood
School Age Children
Adolescent Children
Young Adult
Empty Nest
Aging Couple

Changes cause stress. Families are constantly changing and moving to different stages in the life cycle. Because of this, adjusting to stress/change becomes a part of most families' life cycle. A family with a child with disabilities usually experiences additional stress. It is important for families to understand that issues change during different stages of a child's life and that these issues affect the entire family. Four life stages are emphasized in this module: early childhood, school age, adolescence, and adulthood. Since change causes stress, it is important that families become aware of that stress and learn ways to handle the stress.

One of the family's key resources for dealing with stress is a family's range of coping strategies. Olson and others (1983) have defined these strategies in two categories: internal and external. Internal coping strategies are designed to make an event less stressful by changing one's perception about it and making it solvable (within the family). External coping strategies are utilizing social and professional resources (outside the family).

Family members, friends, neighbors and relatives are support systems that reduce stress. Families need to become aware of their informal networks and discover methods to utilize these important support systems.

Developing a more balanced life style (work, self, and relationships) is an important skill to reduce stress. Goals that focus on a more balanced life style are recommended and emphasized for each adult in the family. Not only is a balanced life style important for each individual but achieving family balance is also important to reduce stress. Some characteristics of a balanced family are equality, adaptability, cooperation, open communication, planning and cohesion. The main goal of family balance is that each family member learn independence and self assurance to the maximum extent possible.

A family with a child with disabilities needs many skills so that *all* family members can develop to their fullest potential. The awareness of stress and change, and the developing of coping strategies are important first steps.

Overview

The goal of this module is to understand stress and develop support in the family with a child with disabilities.

Objectives

1. Become familiar with the Universal Family Life Cycle.
2. Develop an awareness of issues and stress in the family with a child with disabilities.
3. Discuss factors that determine stress for families and identify the various coping strategies.
4. Select the various informal support systems that reduce family stress.
5. Understand the need for a balanced individual and family life.

Objective Number	Suggested Minutes	Content	Presentation Strategy
	10	Introductions, Objectives and Agenda Review	
1	15	The Universal Family Life Cycle	Lecturette
2	45	Issues and Stressors in the Life Stage of the Family	Individual, Small and Large Group Activity
	10	Break	
3	30	Stressors and Coping Strategies	Lecturette and Large Group Discussion
4	15	Informal Support Systems	Individual Activity
5	15	Balancing Self and Family	Large Group Discussion
	10	Conclusion and Evaluation	Large Group Activity
	150		

Suggested Trainer Agenda

WORKSHOP

TITLE:

Stress and Support in the Family

DATE: _____

PAGE: 1

CLIENT:

GOAL:

Understanding stress and developing support in the family with a child with disabilities.

OBJECTIVES:

1. Become familiar with the Universal Family Life Cycle.
2. Develop an awareness of issues and stress in the family with a child with disabilities.
3. Discuss factors that determine stress for families and identify the various coping strategies.
4. Select the various informal support systems that reduce family stress.
5. Understand the need for a balanced individual and family life.

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
10 minutes		Welcome Introductions Objectives and Agenda Review Display objectives and Agenda on chart paper		 Chart Paper Pens Tape
15 minutes		<u>The Universal Family Life Cycle</u> Activity/Handout/Overhead 1 Lecturette Distribute Handout 1 Display Overhead 1 Discuss the various stages with class participants. All families experience change as members are born, grow up, leave home and bring in new members through marriage or other relationships. All families experience stress as normal changes and unexpected changes occur. The family who has a child with a disability usually experiences additional stress. It is important to understand how families change over time and how those changes affect their needs and attitudes toward a child with disabilities. The following is known as the Universal Family Life Cycles:	View Overhead 1 Participate in discussion of various life stages. Answer: "What life cycle is your family experiencing?"	 Overhead Projector Screen  Overhead 1  Handout 1

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
45 minutes		Couple Young Children (Early Childhood) School Age Children Adolescent Children Young Adult (Adulthood) Empty Nest Aging Couple Ask participants what life cycles their family is experiencing. <u>Issues and Stressors in the Life States of the Family with a Child with Disabilities</u> Activity/Handout 2 Individual, Small and Large Group Activity Distribute Handout 2 • Complete individual survey. Circle the level of stress you have experienced or think you might experience with each issue listed in the four life stages. When you have completed this activity we will meet in small groups and discuss the issue that caused/will cause you the most stress in each life stage. • Small group discussion and large group report. Divide into small group, identify a facilitator and a recorder. Each person will answer the following questions. The recorder should record answers on chart paper and report back to large group. (1) What issue caused you the most stress in early childhood? school age? adolescence? adulthood? (2) How did you eventually handle the stress you experienced? (3) What stress do siblings and grandparents experience in each of the life stages. Break	Circle level of stress for each question. • Divide into small groups of 4. • Identify facilitator and recorder. • Answer question. Record answers. Report back.	 Handout 2  Chart paper
14 10 minutes		Break		15

TIME

WHO

PARTICIPANT ACTIVITIES

**HANDOUTS
MEDIA**

Listen

Handout 3

All families who have children experience stress. The facts that determine the amount of stress for families who have children with disabilities and various coping strategies that families develop are listed below.

1. Severity of disability
2. Perception of the disability
3. Family's strength and resources (developing support in the family and extended family)
4. Community Resources (working with professionals)
5. Other critical events occurring in family (death, divorce, financial problems, moving, etc.)

**Answer question.
Participate in discus-
sion.**

Note: The subject matter of this activity is obviously very personal. Participants, depending on their level of comfort with the group, may not want to share the *most* stressful thing in their family. The trainer *must* be very aware of audience reaction. The trainer may share an example and then simply ask the group to reflect on their stressors and acknowledge that they exist.

As we shall see in our discussion of family life cycle, stress may result from a number of developmental or situational changes. The family may not only respond to these stresses with a variety of

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
00 18		coping strategies, but also may feel more stressed (and therefore respond more quickly) to some stressors than to others. Another important concept is the fact that coping strategies may while reducing stress in some areas, actually produce stress in some other area (McCubbin, et al., 1980). For example, feeling guilty about a child's disability may serve as a coping strategy for some parents because their guilt "explains" the disability and makes the world seem more controllable (Gardner, 1971). Yet guilt feelings are themselves stressors. It is important for service providers to realize that seemingly counterproductive actions may well be serving a real purpose in reducing a family's stress in some area, and that the stresses addressed by that action must be the ones that are (currently) most important to the family. It follows that we must help the family find a new coping strategy that addresses those stresses without the counterproductive effects. McCubbin and Patterson (1981) consider coping strategies to be either internal--using resources within the family--or external --using resources outside the family. They developed five major classifications of strategies within these two broad categories. They are: Internal Strategies <i>Passive appraisal</i> - avoiding or denying a problem in the hope that it will "go away". <i>Reframing</i> - analyzing or redefining a problem so it may be solved or viewed in a less stressful way. External Strategies <i>Social support</i> - acquiring and using resources from the extra-familial network. <i>Spiritual support</i> - acquiring and using spiritual interpretations. <i>Formal support</i> - acquiring and using professional help. We will look at each of these strategies more closely.		19

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
20		<i>Passive Appraisal:</i> This strategy was least often used in a nationwide study of the coping strategies of one thousand families (Olson, McCubbin, Barnes, Larsen, Muken, & Wilson, in press). Passive appraisal in families with disabled members may take the form of denial, anger, withdrawal. These are the strategies often employed in the period immediately following the diagnosis or identification of the disability and is considered a normal response to tragedy (Vernon, 1979). While most families pass beyond this phase and successfully confront the reality of disability, it is important to realize that families may go through more than one crisis related to the disability as they move through the life cycle, and may revert to this strategy more than once (Turnbull, Brotherson, & Summers, in press). Another passive appraisal strategy is a refusal to think about the future. Many of the families who were talked to spoke of living "one day at a time." This has the effect of reducing the sheer number of things the family must worry about. Also, problems in the future (e.g. where will the disabled person live? What happens when the parents die?) seem much more overwhelming than day to day worries such as scheduling and physical care. A family refusal to plan for the future may be a barrier to teaching the disabled person more independent living skills. For example, it is easier in the short-run to continue to dress a disabled person than to teach him or her to dress alone. The long-run benefits of greater independence and elimination of a time-consuming chore for other family members is ignored if the family cannot see into the future. <i>Reframing:</i> One important reframing strategy is rational problem solving. Families placing a high value on science and having a strong belief in their ability to control their environment may frequently employ rational problem solving to reduce stress. One disabled adult described his family's approach to problems this way: We never looked at a situation as something we couldn't handle. Whenever somebody had a problem, we always talked it out, consider the pros and cons of all the alternatives. We always knew we could count on each other for help.		21

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
C 23		Another reframing technique involves making attitude adjustments. This is the philosophy behind the saying "When life hands you a lemon, make lemonade." Attitude adjustment may take the form of positive comparisons of the disabled person with other disabled people, and concluding that, after all, things could have been worse. For example, one mother of a moderately retarded adult said: We're lucky because Carol isn't aware she's different. I know lots of others who are very hurt because they know they're retarded. But Carol is too handicapped to be hurt by her limitations. Other families may use selective attention, that is, they may focus on positive attributes in stressful situations or on strengths of the disabled person. A father of a severely cerebral palsied young woman said: We're lucky Denise has been healthy - she's never been sickly. The only real expense has been the electric wheelchair - otherwise she's been no more expensive than any other child. Finally, some families learn to recognize their successes and use them to build confidence and self esteem. This strategy seems particularly important in view of research findings that self esteem is perhaps the key resource that families can bring to bear on a stressful situation (McCubbin, et al., 1980). This is difficult for families with disabled members to do, since service providers tend to focus on problems or barriers. A family that feels good about its successes can find strength to tackle more problems. <i>Social Support</i> as a coping strategy involves reliance on friends and extended family for emotional and practical help in stressful situations. Although the availability of a social support network varies, families also vary in their ability to use support effectively. Not everyone knows how to accept help from their friends.		23

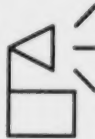
Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
24		<i>Spiritual Support</i> was the most often used coping strategy in a national study of families (Olson, et al., in press). Personal interpretations of religious teachings seem to be more helpful to families with disabled members than formal church participation (Bristol & Schopler, 1983; Summers, Brotherson, Turnbull, in press). These personal interpretations can take a wide variety of forms. Here are some of the interpretations given by families interviewed: God must think I'm a pretty strong person to trust me with all these problems. We just tried to do our best and trusted in the good Lord to look after us. I think God has a plan for that boy. I thought I would be helped (by God) if I helped others. The most important support for me was a book by Alan Watts on Zen. It taught me to accept what I can't change with serenity. Service providers should recognize and encourage the use of spiritual support as a coping strategy. This may involve enlisting the aid of local clergy and providing them with more information about disabilities, so they can be an effective resource. <i>Formal Support.</i> Effective use of professionals and public support involves both the ability and the willingness to seek out and use them. Families with a strong distrust of outsiders or a strong belief in "making it on our own" may find this difficult to do. Also negative experiences with professionals who are insensitive or incompetent may curtail the family's willingness to seek out other help. Finally,		25

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
15 minutes		effective use of formal support requires skill in advocating for one's needs. Families need to learn assertiveness as well as more information about the services available in their locality. There are many more specific coping strategies than the ones we have highlighted here. Every family utilizes its membership characteristics and its cultural style to develop its own unique patterns of coping. Note: This information on coping strategies was taken directly from: Summers, J., Brotherson, M.J., Turnbull, A. "Working With Families With Disabled Members: A Family Systems Approach" Lawrence, KS: University of Kansas, Bureau of Child Research, 1983. The trainer will want to become familiar with the content and use his/her own words to explain the internal and external coping patterns. <u>Informal Support Systems</u> Activity/Handout 4 Individual Activity Families, friends, neighbors and relatives are support systems that reduce stress over the life cycle of children with disabilities. Please go over this list and check the areas of support you are using or have used in the past. Take informal survey of participant responses. How many checked parents, friends, etc. If time permits, share answers to questions below. If not, have participants ponder these questions individually. Questions to Ponder/Discuss: 1. In what ways have these individuals been most helpful? 2. If I want to receive more help from any one person, what do I need to do?	Complete Checklist. Share responses.	 Handout 4 27

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA																								
15 minutes		<u>Balancing Self and Family</u> Activity/Handout/Overhead 5 Large group discussion Distribute Handout 5 Display Overhead 5A - Refer to Handout 5 (page 1) "Balanced Individual Life Style" <table border="1" style="width: 100%;"> <tr> <th colspan="2">Relationships</th> <th colspan="2">Self</th> </tr> <tr> <td>Spouse</td> <td>Co-workers</td> <td>Leisure</td> <td>Exercise</td> </tr> <tr> <td>Children</td> <td>Relatives</td> <td>Mental</td> <td>Spiritual</td> </tr> <tr> <td>Friends</td> <td></td> <td>Emotional</td> <td></td> </tr> </table> <table border="1" style="width: 100%;"> <tr> <th colspan="2">Life Work</th> </tr> <tr> <td>House Chores</td> <td>Career development</td> </tr> <tr> <td>School</td> <td>Volunteering</td> </tr> <tr> <td>Hobbies</td> <td>Employment</td> </tr> </table> Recommended: 25% - Relationships 25% - Self 50% - Life Work In order to reduce stress, it is recommended that individuals develop a balanced life style: Work, relationships and self.	Relationships		Self		Spouse	Co-workers	Leisure	Exercise	Children	Relatives	Mental	Spiritual	Friends		Emotional		Life Work		House Chores	Career development	School	Volunteering	Hobbies	Employment	Study page 1 of Handout 5	 Handout 5  Overhead 5A
Relationships		Self																										
Spouse	Co-workers	Leisure	Exercise																									
Children	Relatives	Mental	Spiritual																									
Friends		Emotional																										
Life Work																												
House Chores	Career development																											
School	Volunteering																											
Hobbies	Employment																											

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
		Discussion Questions: - Does your life need a better balance? - In which area would you like to work on to improve your life style? Display Overhead 5B - Refer to Handout 5 (page 2) Family Balance - Philosophy - Equality - Adaptability - Cooperation - Open Communication - Planning - Cohesion Briefly elaborate on the characteristics of a balanced family. The goal of a balanced family is to allow each family member to learn independence and self-assurance to the maximum extent possible. Some characteristics of a balanced family are: Philosophy: The adults in the household agree to try for as normal a family life as possible, and recognize the rights, needs and preferences of each member. This means that the child with disabilities will not be a privileged character in their home. Equality: No family member is considered more important than any other. The parents and each child are presumed to have basic rights, personal needs, ideas and preferences. This	Participate in large group discussion relative to the discussion questions Listen, refer to Handout 5, page 2.	Handout 5 Overhead 5B

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
		means the family as a unit has a responsibility to each family member, parents and children alike. 3. Adaptability: Families with children with disabilities have more to do than other families. There is an agreement in the family that "we may have to do things differently." The object is to get things done the best way for the family. 4. Cooperation: Members of the family work as a team. It is a statement that there are things that need to be done if this family organization is to run smoothly for the benefit of all. 5. Open Communication: There is room for discussion of problems. Negative feelings are dealt with openly. Open communication allows for goal setting. Everyone's ideas are considered in the process. 6. Planning: Family work is planned day by day as well as planned ahead. Planning allows members not to feel trapped with no alternatives. Fun must also be planned. 7. Cohesion: Members develop their individual interests and decisions, but look upon the family as a unit for closeness, support and "common family time." Questions to Ponder: 1. Which characteristic is your family's strength? 2. Which characteristics would you like to improve? Ending statement for all participants to share with group.		

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
10 minutes		The one character that is my family's strength is _____. Use this as a whip. Participants can complete whip or pass. <u>Conclusion:</u> Restate objectives. Thank participants. Complete Evaluation/Handout 6.	Complete evaluation	 Handout 6

The Universal Family Life Cycle

All families experience change as members are born, grow up, leave home and bring in new members through marriage or other relationships. All families experience stress as normal changes and unexpected changes occur. The family who has a child with a disability usually experiences additional stress. It is important to understand how families change over time and how these changes affect their needs and their attitudes toward a child with a disabilities. The following is know as the Universal Family Life Cycle:

Couple
Early Childhood
School Age Children
Adolescent Children
Adulthood
Empty Nest
Aging Couple

What life cycle(s) is your family experiencing?

The Universal Family Life Cycle

Couple

Early Childhood

School Age Children

Adolescent Children

Adulthood

Empty Nest

Aging Couple

Issues and Stressors in the Life Stages of the Family With a Child With Disabilities

Four life stages of a child with disabilities are listed below: early childhood, school age, adolescence and adulthood. Also listed are some issues that families may experience during that life stage. Stress usually occurs with change and the process of learning new skills to handle that change.

Please circle the level of stress you have experienced or think you might experience with each issue listed in the four life stages. When you have completed this activity, we will meet in small groups and discuss the issue that caused/may cause you the most stress in each life stage.

Life Stage of A Child with Disabilities	Levels of Stress Issues for Families (especially parents)	Not Much--A Lot			
		1	2	3	4
Early Childhood	1. Accepting the handicapped.	1	2	3	4
	2. Informing family and friends.	1	2	3	4
	3. Locating and coordinating services.	1	2	3	4
	4. Determining type of placement: home, school or community.	1	2	3	4
	5. Transitioning to school age.	1	2	3	4
School Age	1. Deciding on an appropriate placement.	1	2	3	4
	2. Developing leisure time activities.	1	2	3	4
	3. Identifying strengths and build- ing child's self esteem.	1	2	3	4
	4. Getting appropriate child care.	1	2	3	4
	5. Transitioning to adolescence.	1	2	3	4
Adolescence	1. Handling sexuality and social life issues.	1	2	3	4
	2. Planning for a career or vocation.	1	2	3	4
	3. Developing independence for the child with disabilities (letting go).	1	2	3	4
	4. Accepting the handicap and its limitations for future independ- ence.	1	2	3	4
	5. Transitioning to adulthood.	1	2	3	4

Life Stage of A Child with Disabilities	Levels of Stress Issues for Families (especially parents)	Not Much--A Lot			
		1	2	3	4
Adulthood	1. Working with adult services.	1	2	3	4
	2. Finding appropriate living arrangements.	1	2	3	4
	3. Determining guardianship for a child with disabilities.	1	2	3	4
	4. Planning for the individual with disabilities to become his/her own self advocate.	1	2	3	4
	5. Determining the future of marriage and a family for the child with disabilities.	1	2	3	4

Please go back to each life stage and star (*) the issue that caused or may cause you the greatest stress.

Adapted from: P-PACT Training Manual (a federal project). San Diego, CA: San Diego State University, Department of Special Education, 1986.

Adapted from: Summers, J., Brotherson, M.J. and Turnbull, A. *Working with families with disabled members: A family systems approach*. Lawrence, KS: University of Kansas, Bureau of Child Research, 1983.

Stressors and Coping Strategies

All families who have children experience stress. The factors that determine the amount of stress for families who have children with disabilities and various coping strategies that families develop are listed below.

Stressors: Factors that may determine stress for parents of children with disabilities.

1. Severity of disability.
2. Perception of the disability.
3. Family's strength and resources (developing support in the family and extended family).
4. Community resources (working with professionals).
5. Other critical events occurring in family (death, divorce, financial problems, moving, etc.).

Discussion question:

Which of the above items has caused your family the most stress?

Coping Strategies: Anything the family does to reduce stress.

Internal (within the family):

1. Passive Appraisal
Ignoring or setting aside a problem (can be a relaxing activity or a denial of the problem).
2. Reframing
Thinking about a problem in a positive way and solving within self or family.

External (outside the family):

3. Spiritual Support
Developing a belief system that makes a situation more understandable.

4. Social Support

Getting practical and emotional support from friends, neighbors, relatives, etc.

5. Professional Support

Using professional help and seeking community resources.

Discussion question:

Identify a highly stressful experience in the past year. Which of the above coping strategies did you use and how effective was it? Share this coping strategy with the group.

Adapted from: P-PACT Training Manual (a federal project). San Diego, CA: San Diego State University, Department of Special Education, 1986.

Adapted from: Summers, J., Brotherson, M.J. and Turnbull, A. *Working with families with disabled members: A family systems approach*. Lawrence, KS: University of Kansas, Bureau of Child Research, 1983.

Informal Support Systems

Immediate family members, other relatives, friends and neighbors form an informal support system that can help reduce stress during the life cycle of a child with disabilities. Please go over this list and check the areas of support you are using or have used in the past.

- _____ 1. My parents
- _____ 2. My spouse's parents
- _____ 3. My own relatives
- _____ 4. My spouse's relatives
- _____ 5. My husband or wife
- _____ 6. My friends
- _____ 7. My spouse's friends
- _____ 8. My own children
- _____ 9. My neighbors
- _____ 10. My co-workers

Questions to Ponder/Discuss:

1. In what ways have these individuals been most helpful?
2. If I want to receive more help from any one person, what do I need to do ?

From: Mendoza, J. *Search: Exploring the systems of family support*.
San Diego, CA: San Diego State University, Special Education Project IINTACT, (in print).

Balancing Self and Family

Balanced Individual Life Style

Relationships		Self	
Spouse	Co-Workers	Leisure	Exercise
Children	Relatives	Mental	Spiritual
Friends		Emotional	
Life Work			
	House Chores	Career Development	
	School	Volunteering	
	Hobbies	Employment	

Recommended percentages: 25% - Relationships
 25% - Self
 50% - Life Work

In order to reduce stress, it is recommended that individuals develop a balanced life style: work, relationships, and self.

Discussion Questions:

1. Does your life need a better balance?
2. In which area would you like to work on to improve your life style?

Family Balance

The goal of a balanced family is to allow each family member to learn independence and self-assurance to the maximum extent possible.

Some characteristics of a balanced family are:

1. **Philosophy:** The adults in the household agree to try for as normal a family life as possible, and to recognize the rights, needs and preferences of each member. This means that the child with disabilities will not be a privileged character in their home.
2. **Equality:** No family member is considered more important than any other. The parents and each child are presumed to have basic rights, personal needs, ideas and preferences. This means the family as a unit has a responsibility to each family member, parent and child alike.
3. **Adaptability:** Families with children with disabilities have more to do than other families. There is an agreement in the family that "we may have to do things differently." The object is to get things done the best way for the family.
4. **Cooperation:** Members of the family work as a team. It is a statement that there are things that need to be done if this family organization is to run smoothly for the benefit of all.
5. **Open Communication:** There is room for discussion of problems. Negative feelings are dealt with openly. Open communication allows for goal setting. Everyone's ideas are considered in this process.
6. **Planning:** Family work is planned day by day as well as planned ahead. Planning allows members not to feel trapped with no alternatives. Fun must also be planned.
7. **Cohesion:** Members develop their individual interests and decisions, but look upon the family as a unit for closeness, support and "common family time."

Adapted from Clifford, Charlotte. *Parental skills for parents of handicapped children*. Houston, TX: Interaction, Inc.

Balanced Individual Life Style

Relationships Spouse Co-workers Children Relatives Friends	Self Leisure Exercise Mental Spiritual Emotional
Life Work House chores Career development School Volunteering Hobbies Employment	

Family Balance

- 1. Philosophy**
- 2. Equality**
- 3. Adaptability**
- 4. Cooperation**
- 5. Open Communication**
- 6. Planning**
- 7. Cohesion**

Stress and Support in the Family

Summary

All families experience change as members are born, grow-up, leave home, and bring in new members or other relationships.

Changing Life Stages of a Family

Couple
Early Childhood
School Age Children
Adolescent Children
Young Adult
Empty Nest
Aging Couple

Families having a child with a disability experience additional stress at various stages in this cycle as changes occur and the need to learn new skills arises.

Stressors

- Severity of Disability
- Perception of the Disability
- Family's Strength and Resources
- Community Resources
- Other Critical Events Occurring in Family

Coping Strategies

Internal (within the family)

- Passive Appraisal
- Reframing

External (outside the family)

- Spiritual Support
- Social Support
- Professional Support

Immediate family members, other relatives, friends and neighbors form an informal support system that can help reduce stress during the life cycle of a child with disabilities.

Informal Support System

Parents
Spouse's Parents
Own Relatives
Spouse's Relatives
Husband or Wife
Friends
Spouse's Friends
Own Children
Neighbors
Co-Workers

Each individual family member and the family as a whole can reduce stress by striving for a balanced life style.

Individual

Relationships

- spouse
- children
- friends
- co-workers
- relatives

Self

- leisure
- exercise
- mental
- spiritual
- emotional

Life Work

- house chores
- career development
- school
- volunteering
- hobbies
- employment

Family

Philosophy
Equality
Adaptability
Cooperation
Open Communication
Planning
Cohesion

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Evaluation

Your responses to the questions/statements below will assist us in improving this module. Please respond to all items. Your participation in this evaluation is completely *anonymous*. DO NOT place your name anywhere on this evaluation.

Based on a scale of 1 through 10, how much of the information presented was new to you?

_____ 1 is not much new; 10 all new.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1. After this session, I am aware of the Universal Family Life Cycle.	1	2	3	4	5
2. This session helped me identify factors that cause stress in my family.	1	2	3	4	5
3. Because of this session, I am aware of various coping strategies that reduce stress.	1	2	3	4	5
4. This session helped me identify my informal support systems.	1	2	3	4	5
5. After this session, I have gained knowledge about a balanced individual and family life.	1	2	3	4	5
6. The material presented was sensitive to all cultural groups.	1	2	3	4	5
7. The material covered information which was appropriate to all handicapping conditions.	1	2	3	4	5
8. The material presented matched my needs.	1	2	3	4	5
9. I will use some of the information/resources that were introduced.	1	2	3	4	5
10. The instructors did a good job.	1	2	3	4	5

11. Specific suggestions to improve this module:
